

Inequity and Vulnerability in End of Life Care: Ethical Analysis

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Inequity and vulnerability

- Popular words in health research and policy
 - Often used with ethical connotation but without precise definitions
 - Their relationship rarely discussed

Inequity

- Inequality \neq inequity
 - Inequality = difference
 - Inequity = unfairness and injustice
 - Inequalities that are ethically or morally problematic
- Various definitions of inequity possible
- Precise definitions rarely defined

Vulnerability

- Implies special attention
- Examples of vulnerable populations identified:
 - Aboriginal peoples, immigrants, people with disabilities, homeless, high risk mothers, persons with AIDS, the mentally ill and disabled, alcohol or substance abusers, ...
- “Subgroup approach” (Kipnis 2001, 2003): designating certain groups as vulnerable without examining its criteria and societal responsibility
 - Eventually, virtually everyone identified as vulnerable
 - Risk of stereotyping everyone in the group identified as vulnerable

Objective

- To clarify:
 - the meaning of inequity and vulnerability, and
 - their relationship
- Within the context of health care, end of life care, in particular
 - End of life care is often overlooked
 - Inequity and vulnerability in end of life care is virtually unnoticed

Risk chain model

- Developed by Alwang, Siegel, and Jorgensen (2001, 2002) for international development work
- Useful to understand how vulnerability occurs

Risk

Factors that increase
likelihood of
undesirable outcome



Risk response

Options to manage
the risk



Outcome

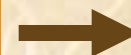
Risk

Factors that increase
likelihood of
undesirable outcome

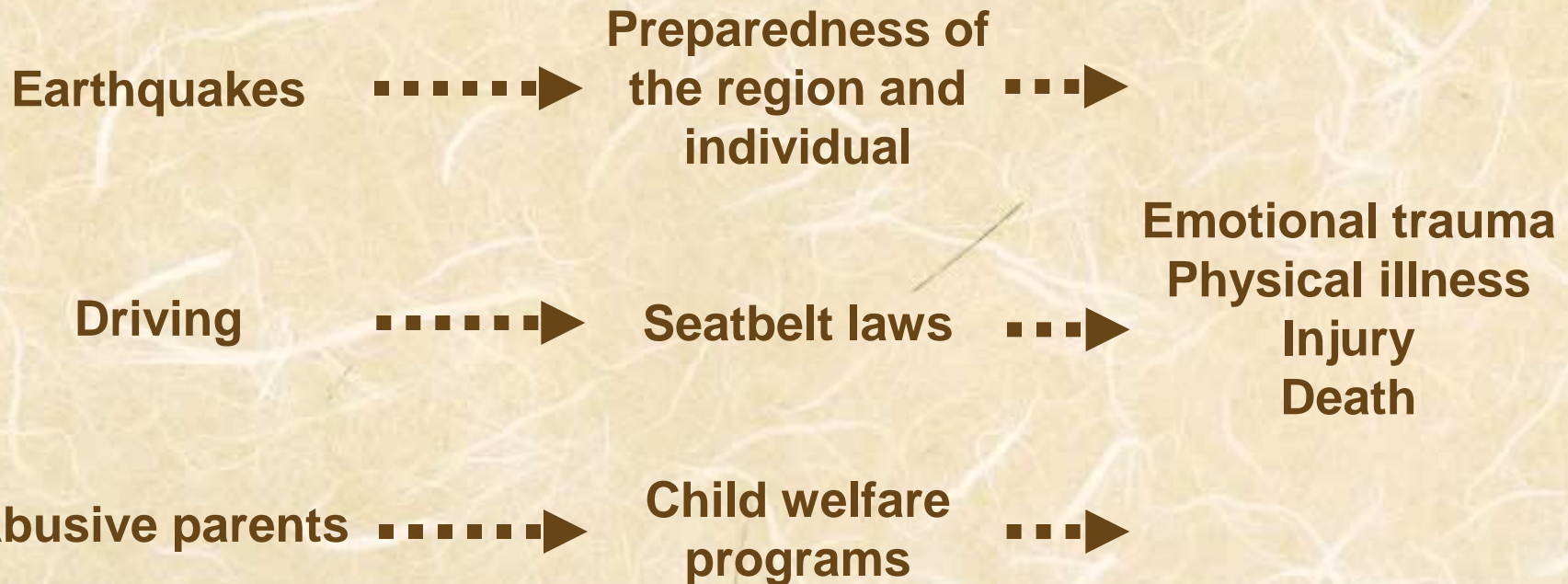


Risk response

Options to manage
the risk



Outcome



Insights from the risk chain model

- Identifying the outcome of interest is a critical first step for defining vulnerability
- Distinguishing risk and risk response avoid stereotyping the vulnerable
- The risk chain model itself is empirical rather than normative

Big party

Risk

Factors that increase
likelihood of
undesirable outcome

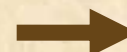
**Limited amount
of alcohol at the
party**

Risk response

Options to manage
the risk

**Crack and
Smash of
glasses**

Outcome



Being hit by
lightening

Risk

Factors that increase
likelihood of
undesirable outcome



Do not play in
bad weather

Risk response

Options to manage
the risk



Death in the
golf course

Outcome

Being hit by
lightening

Do not play in
bad weather

Death in the
golf course

Risk

Factors that increase
likelihood of
undesirable outcome



Risk response

Options to manage
the risk



Outcome

Being hit by
the golf ball

Observe safety
measures

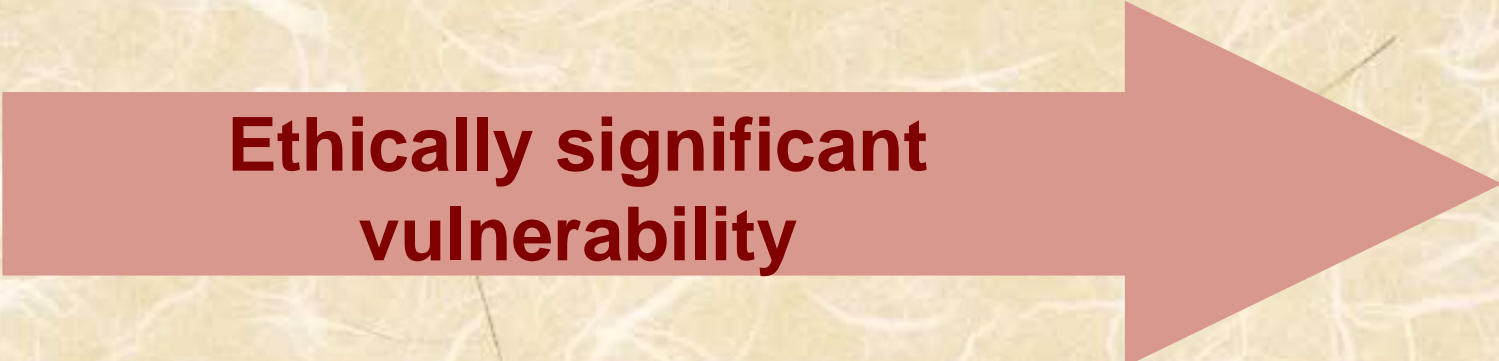
Ethically significant vulnerability



The vulnerable: those who are at risk of being treated inequitably

Inequity

**Ethically significant
vulnerability**



Risk

Factors that increase
likelihood of
undesirable outcome



Risk response

Options to manage
the risk



Outcome

Inequity



- The risk chain model
 - offers a useful foundation upon which we examine vulnerability, yet
 - lacks an ethical component to guide judgments concerning what risks, risk responses, and outcomes are ethically problematic

In what way does the outcome occur?
(Some risks are ethically significant while others not)

Can people safeguard their own
needs and interests adequately?

Risk

Factors that increase
likelihood of
undesirable outcome



Risk response

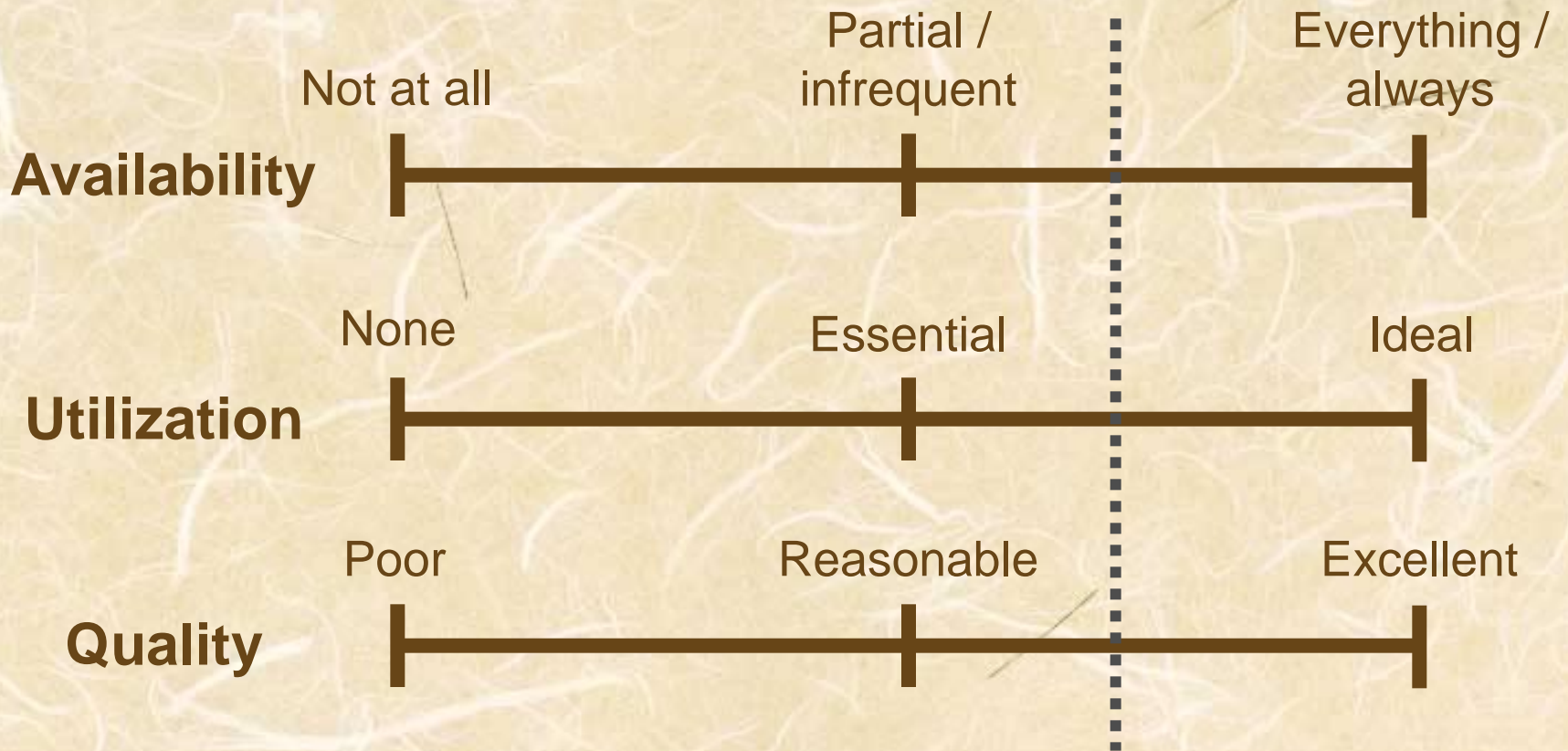
Options to manage
the risk



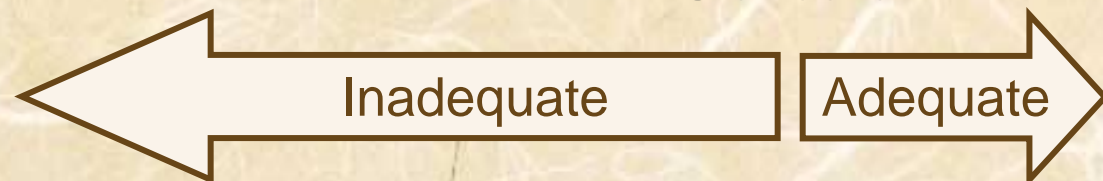
Outcome

Is the outcome ethically significant?

- What is the outcome?
 - Inadequate end of life care



Standard



- Is end of life care ethically significant? – Yes!
 - Norman Daniels's normal species functioning view (1985, 2007)

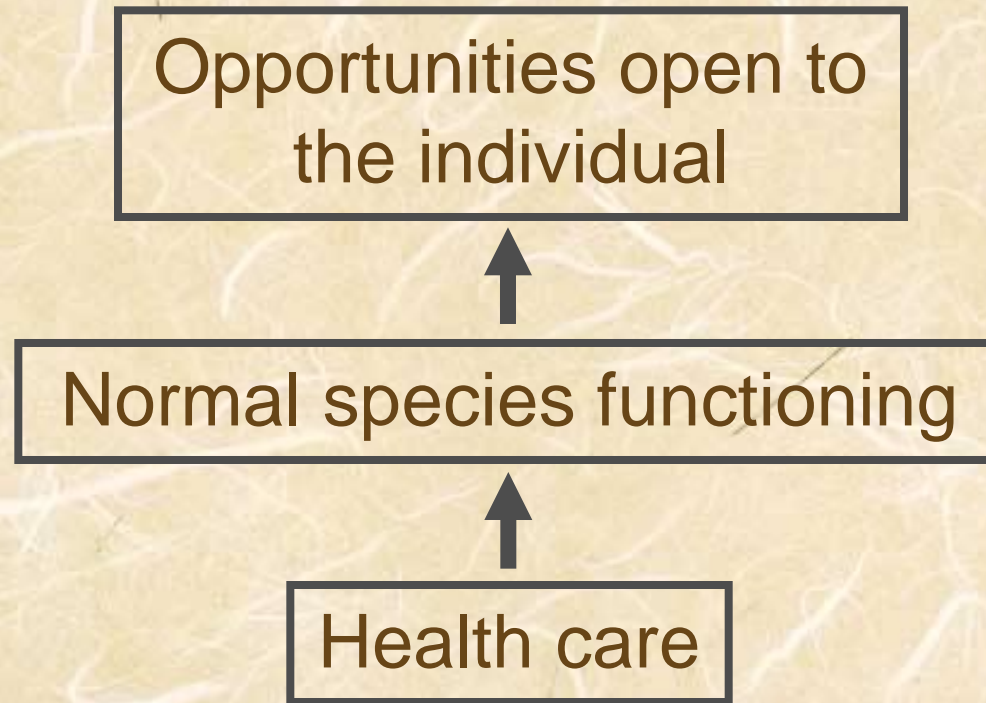
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Normal species functioning

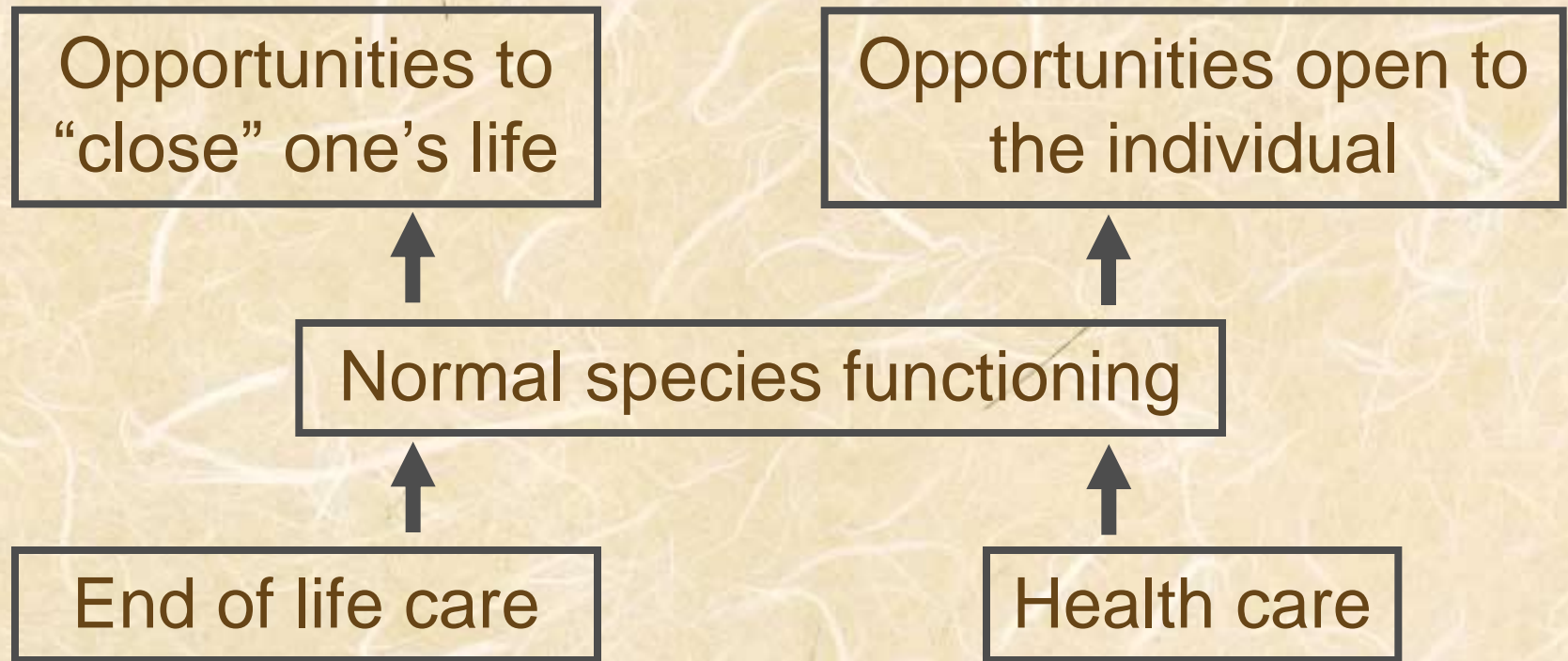
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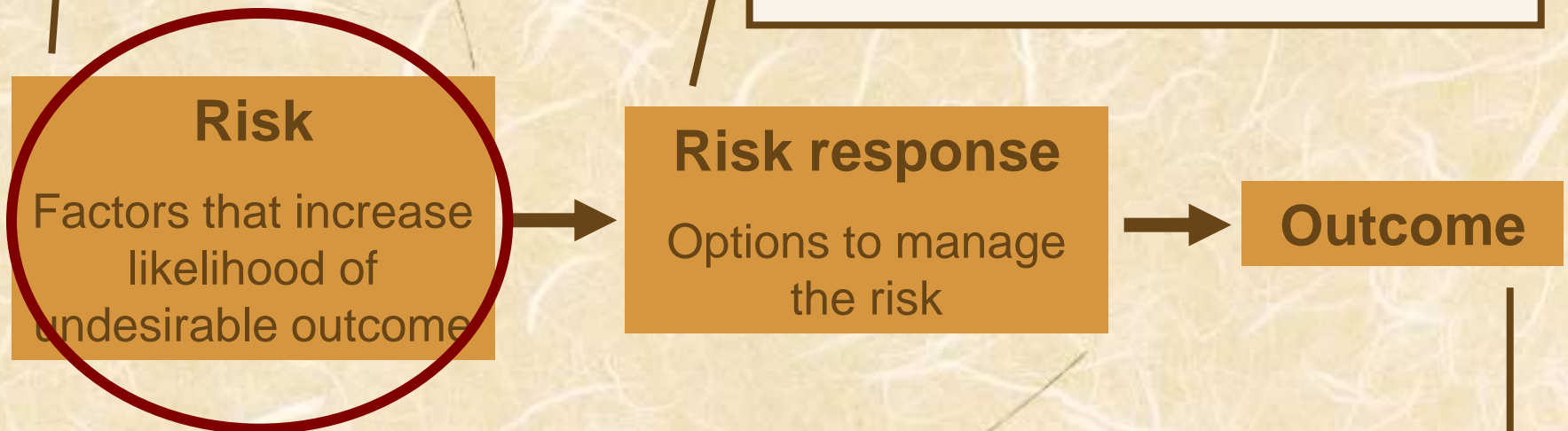


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 - Norman Daniels's normal species functioning view (1985, 2007)



In what way does the outcome occur?
(Some risks are ethically significant while others not)

Can people safeguard their own
needs and interests adequately?



Is the outcome ethically significant?

Risks of inadequate end of life care

- Choice
 - e.g., fully informed free refusal
- Unmet social obligation
 - Society fails to do something that it has an obligation to do
 - e.g., prejudice, lack of transportation, and complex system
- Nobody's fault
 - Risks beyond our control (bad luck or biological mechanism)
 - e.g., dying with “orphan” diseases or an illness that requires complex care

Risks of inadequate end of life care

- ~~Choice~~
 - e.g., fully informed free refusal
- Unmet social obligation
 - Society fails to do something that it has an obligation to do
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- Nobody's fault
 - Risks beyond our control (bad luck or biological mechanism)
 - e.g., dying with “orphan” diseases or an illness that requires complex care

Risks of inadequate end of life care

- ~~Choice~~
 - e.g., fully informed free refusal
- **Unmet social obligation** **Justice**
 - Society fails to do something that it has an obligation to do
 - e.g., prejudice, lack of transportation, and complex system
- Nobody's fault
 - Risks beyond our control (bad luck or biological mechanism)
 - e.g., dying with “orphan” diseases or an illness that requires complex care

Risks of inadequate end of life care

- ~~Choice~~
 - e.g., fully informed free refusal
- **Unmet social obligation** **Justice**
 - Society fails to do something that it has an obligation to do
 - e.g., prejudice, lack of transportation, and complex system
- **Nobody's fault** **Compassion**
 - Risks beyond our control (bad luck or biological mechanism)
 - e.g., dying with “orphan” diseases or an illness that requires complex care

From ethical analysis of risks...

- End of life care is inequitable, when:
 - adequate end of life care is not offered, or
 - utilization or quality of end of life care is inadequate due to unmet social obligation or nobody's fault
- The vulnerable are those at risk of being treated inequitably
- The vulnerable are, for example:
 - Persons with low socioeconomic status, disability, or minority status
 - Persons with illness requiring complex care or orphan disease

In what way does the outcome occur?
(Some risks are ethically significant while others not)

Can people safeguard their own
needs and interests adequately?



Is the outcome ethically significant?

- Some people “may be less able than others to safeguard their own needs and interests adequately” (Agency for Health Care Policy and Research 1998)

From ethical analysis of risk responses...

- End of life care is inequitable, when:
 - utilization or quality of end of life care is inadequate as a result of the lack of resources available to persons
- The vulnerable are, for example:
 - Persons with low socioeconomic status or minority status
 - Children
 - The severely mentally ill

Inequity

- Adequate end of life care is not offered,
- Utilization of or quality of end of life care is inadequate due to unmet social obligation or nobody's fault, or
 - Persons with low socioeconomic status, disability, or minority status
 - Persons with illness requiring complex care or orphan disease
- Utilization or quality of end of life care is inadequate as a result of the lack of resources available to persons
 - Persons with low socioeconomic status or minority status
 - Children

Vulnerable persons

What this work adds

- The risk chain model:
 - prevents us from stereotyping persons with a group characteristic, and
 - allows us to investigate further heterogeneity among the vulnerable
- The extended risk chain model offers:
 - reasons for our intuitive identification of vulnerable populations, and
 - a language to discuss further what we mean by vulnerability and inequity

Questions and Discussion